Beyond the Minimum Data Set: Measuring Disruptive Behaviors in Nursing Home Residents. Do We Need Better Psychometrics or Simply Different Metrics?

Adrian Leibovici, MD

Nothing can be more disruptive, disheartening, and taxing of a nursing home’s resources than the behavioral disturbances of its dementia residents. Unquestionably in the past 25 years there has been progress in tackling the problem of dementia-related agitation in long-term care facilities. The seminal work of Cohen-Mansfield brought about a systematic description of otherwise heterogeneous behaviors and, even more important, a conceptualization of agitation as a syndrome: we now describe agitated behaviors as aggressive or nonaggressive, verbal or physical, or repetitive or socially inappropriate. We have created clinical algorithms to identify singular or co-occurring causative factors, mitigating or exacerbating circumstances, response to therapeutic interventions, and so forth.

The practice of simply oversedating agitated residents with high doses of medication or physically interfering with their ability to move around by using tilted recliners, difficult-to-remove table trays, or even more explicit restraints is being phased out under the weight of regulatory scrutiny, public outcry and, yes, advances in our clinical ability to understand and manage dementia-related behavioral problems.

After 1991, it became a federal mandate that all long-term care (LTC) facilities licensed to participate in the Medicaid program should assess, document, and report behavioral disturbances of their residents. The vehicle chosen was the “Behavioral section” or “section E4” of the so called Minimum Data Set (MDS) and Resident Assessment Instrument (RAI), containing elements of a comprehensive clinical and functional status assessment as legislated a few years earlier (Omnibus Budget Reconciliation Act of 1987). Since then, virtually all LTC residents would be described behaviorally in relatively precise terminology on admission, every 3 months, at discharge, and each time there is a “significant change in status.” The original intent of the regulation was to allow for more informed care plans for individual residents but, gradually, the scope of the MDS expanded to characterizing the institutions themselves from the point of view of quality and burden of care. From a tool intended to improve care of specific patients, the MDS became an institutional report card able to determine how a facility would be rated among others and more importantly, how the government would reimburse it.

Questions about the reliability and validity of the MDS in general and of its behavioral section in particular emerged, along with concerns about the resources involved in the collection and transmission of data.

In this issue of the Journal of the American Medical Directors Association, Dr. Ashok Bharucha and his colleagues take a critical look at the ability of the Minimum Data Set in identifying abnormal behaviors in nursing home residents. The method used is to compare the MDS with time-honored behavioral psychometric instruments used in dementia, like the Ryden Aggression Scale and the Cohen-Mansfield Agitation Inventory. Not surprisingly, they found that the MDS grossly underestimated both the total number of residents with agitation as well as the number of residents displaying domain-specific behaviors like verbally aggressive, physically aggressive, and socially objectionable behaviors. They further identified temporal instability of agitated behaviors as an important cause for the lower sensitivity of the MDS compared with the other 2 behavioral scales and in consequence suggest that caregivers should complete behavioral checklists twice daily during the week of reference for MDS completion, which would improve the accuracy of data. There is no question that reliance on actual behavioral observations by caregivers familiar with the resident, in contrast to the current practice of registered nurses doing chart reviews of residents they know little about, would be an improvement. But how much better and how much more useful could the MDS become? In the discussion section of their excellent article the authors touch on some of the conceptual and logistical limitations associated with the MDS as a tool for characterizing behaviors in LTC residents.

The accuracy of behavioral observations is subject to reporting bias even in those most familiar with a resident. Reis and colleagues describe such sources of subjective distortion.
in rating behavior over a time interval. The overall impression is influenced more by events taking place closer to the time of assessment (recency): a resident who has 2 calmer days at the time of assessment preceded by severe screaming for many days in a row will be perceived as less agitated. The more significant a singular event, the more it influences how the entire period is rated (salience): one isolated episode of physical aggression by a resident will weigh heavier in rating his or her behavior than the fact that the resident was calm and cooperative the rest of the time. Reinterpretation of past events is more consistent with a subject’s beliefs rather than with how they actually happened (sense making): a female nursing assistant might perceive a demented male resident’s sexual talk as totally unacceptable and deliberate or more benign and reflective of illness, according to her own values, background, and personal experience with men. The caregivers’ affective response is another source of reporting bias: it matters if they were assigned a heavier load the day of assessment, if they like or dislike a particular resident, if they are dealing with stress in their personal lives, and so forth. How could the MDS or even an “improved MDS” avoid such unintended distortions?

Another challenge is the very nature of agitation in dementia. Behaviors are fleeting and variable in intensity and frequency. It is not uncommon that staff working in different shifts hold totally different images of a resident’s behavioral profile. The night nurse might describe a demented resident with sleep-wake cycle reversal as “wandering and agitated.” The same resident will be “resistive to care” for the day shift staff trying to assist the resident with morning care exactly when he or she is finally able to sleep and “pleasant and posing no management problem” for the evening staff. How does the behavioral section of the MDS perform in such a case?

Even if the data collected have some validity and provide useful information about individual residents and the facilities where they live, it is reasonable to ask if the price of obtaining such information is justified. Those of us who see patients in nursing homes can recall many instances when the MDS specialist (an experienced registered nurse usually) is trying to concentrate in front of the computer and an open chart while 10 feet away a resident screams in pain or another asks to be taken to the bathroom only to have to wait for assistance because of low staffing. How useful should the MDS data be before much-needed clinicians are taken away from providing direct care in order to generate and report such data? Will MDS 3.0, the most recent update of the instrument, alleviate some of these concerns?

Bharucha et al’s article points to limitations in the reliability and sensitivity of the MDS in capturing the scope of behavioral disturbances in nursing home residents. Although based on a small sample, their conclusions are convincing and likely to be replicated in studies using larger samples. More importantly though, their effort should stimulate more discussion and research on the way we gather behavioral information in nursing homes. Such information is very important given the disabling nature of agitation in dementia. The state of the art in clinical data gathering is not satisfactory. Whether using the MDS, or the “gold standard” psychometrics, like the Cohen-Mansfield Agitation Inventory, or simply clinical methods like direct examination and interviewing caregivers, we probably fall short of what is needed. Our observations with all these modalities are discontinuous, subjective, not contemporaneous, and expensive to generate.

One possible solution to this problem might be the integration of technology in the clinical monitoring process. Existing technologies can already provide a fair amount of automated monitoring of motion and behavior of residents with dementia. Even the subjects in Bharucha’s study were part of an observational study using automated video and sensor analysis in a nursing home. The application of mathematical filters has made possible the behavioral analysis of dementia residents monitored with simple motion sensors over long periods of time. The role of the clinician in observing and interpreting behavior is not likely to diminish, but automated monitoring and analysis of behavior could conceivably provide an unobtrusive and less expensive way to collect continuous rather than episodic, truly objective rather than biased, and contemporaneous rather than retrospective data.

REFERENCES